

WV DD Council Quarterly Meeting  
Charleston Marriott Town Center, Charleston, WV  
January 28, 2014

MINUTES

**NOTE:** Due to bad weather and freezing temperatures around the state, and water quality issues in the Charleston area, Members from out of the area were advised not to attend the meeting and no business was conducted. It was an informational session presided over by Kelly Miller, who was the only Executive Committee Member in attendance.

**Members present:** Kathy Butler, Stefanie Caldwell, Jonathan Chaffin, Deborah Davis, Clarice Hausch, Amber Hinkle, Janice Holland, Ann Hubbs, Rickey Meade, Kelly Miller, Beth Morrison, Pat Nisbet, Sheila Paitsel, Tara Roush, Jon Sassi, and LuAnn Summers.

**Members absent:** Greg Bilonick, Sarah Brown, Brent Bush, Joyce Church, Pat Elliott, Betty Holliday, Mary Etta Jones, Jane McCallister, Christina Mullins, Wanda Proffitt, Clark Queen, Jerry Ramsey, Robert Roswall, Tina Tanner, Stacey Thomas, and Melvin West.

**Staff present:** Christy Black, Linda Higgs, and Steve Wiseman.

**Staff absent:** Jim Cremeans

**Guests:** Jenni Sutherland, Bureau of Senior Services.

**Welcome, Introductions, Announcements, and Mission Statement Reminder:**  
Kelly invited everyone to introduce themselves and then asked for any announcements.

Linda announced that cards would be sent around for Members to sign; one for Jane McCallister who is on medical leave and one for Karen Ruddell, who recently retired. Karen's replacement on the Council for Patricia Homberg is Sheila Paitsel.

LuAnn announced that she is temporarily covering the Division of Rehabilitation Services' (DRS) Transition Program until a replacement is found for Susan Wineberger, who has taken another position within DRS.

Steve announced that the Director of the Rehabilitation Services Administration (RSA) will be visiting WV to learn more about the STEP program. This program is the result of a Council funded project which allows teachers to become DRS vendors to assist students in transition, and was carried about by Jeff McCroskey of Community Access, Inc.

Christy announced that Council Member Stefanie Caldwell has been honored by the National Down Syndrome Society (NDSS) as the WV Ambassador of the Year and will be given an award at the upcoming meeting in Washington, D.C. Stefanie has worked with the NDSS and national policymakers towards passage of the Achieving a Better Life Experience (ABLE) Act.

Rickey Meade read the Council's Mission Statement.

**Public Comment:** None

**Legislative Update and PIP Update:** Christy gave Members an update on the bills she is currently following at the Legislature, including proposed cuts included in the Governor's budget bill.

The line item for Independent Living has been decreased from \$500,000 to \$359,810; Family Support decreased from \$985,078 to \$251,226; and the UCED line item decreased from \$318,701 to \$310,196. The line item for Behavioral Health programs was increased from \$67,447,913 to \$75,181,543.

Of particular concern is HB 4244, requiring a person restraining a mentally ill or mentally challenged person in a "four point restraint" to administer sedation by injection at the time the patient is restrained.

HB 4287 is the bill dealing with the administration of medication and health maintenance tasks by approved medication assistive personnel, which Members will hear about later on the Agenda.

A discussion followed about the drastic decrease in the Family Support program's budget and the importance of working for the restoration of funding. Clarice expressed concern that legislators may think the wait list funding is a replacement for Family Support funds (they are not), and feels those funds are insufficient for their intended use. Everyone was encouraged to contact their legislators to explain

the importance of the program. Steve reported that the Council will develop talking points that can be used.

Christy informed the Members that the current Partners in Policymaking (PIP) class recently finished its fourth session, which included the training by Dohn Hoyle on Alternatives to Guardianship. The training was very well received by participants. It was also videotaped for future inclusion on the Council's website.

**Informational session on AMAP proposed legislation:** Tina Maher, the Long-Term Care Program Manager at the Office of Health Facilities Licensure and Certification (OHFLAC), and previous *Olmstead* Coordinator, provided Members a historical context along with current information about the Approved Medication Assistive Personnel (AMAP) legislation being introduced this session.

An AMAP can be used in I/DD Waiver settings and assisted living programs. They are chosen, trained, and supervised by nurses to administer medications and are a less expensive alternative to nursing personnel.

About three years ago the DD Council, the *Olmstead* Council, the Statewide Independent Living Council (SILC) and the Fair Shake Network (FSN) collaborated and successfully got changes to the law in order to allow people to have their medications administered wherever they were in the community (at work, etc.) rather than being required to return to the facility where they lived, or having a nurse appear at their work or other community site to administer medication. The definition of self-administration of medication was also expanded at that time to allow individuals who physically could not take their own medicines receive assistance to do so.

During last year's session, this collaborative group worked with Delegate Fleischauer to add several health maintenance tasks to the list of things that could be delegated to an AMAP. Two constituents in her area were ventilator dependent and were unable to get assistance to remain in their home. One person received State Plan nursing services but became ineligible for those services when he reached age 21. It was felt that if ventilator care could be delegated to an AMAP it would be more affordable to the State for people to receive such services in their homes.

While the final legislation allowed g-tube feedings, insulin injections using pre-measured/filled pens, and other health maintenance tasks to be delegated, vent care

was not included. Instead, an Advisory Committee was established, met five times, and developed recommendations about how to allow vent care dependent people to receive services in their homes by AMAPs. The recommendation sent back to the Legislature was to begin with those individuals who live at home with their families (who would also be providing supports). Other recommendations were to include respiratory therapists in the development of training.

For those people not served through the I/DD Waiver, private duty nursing is only allowed up to age 21. The Advisory Committee recommended this be expanded for those who are receiving vent care as children so they will not “age out” of this needed service. A recommendation was also made to explore delegation for the other two Waiver programs. Some “clean-up” language was also suggested.

Tina mentioned the constraints of the Committee due to the lack of available data; such as how many WV citizens are ventilator dependent, and how many have to go out-of-state for nursing home care (WV nursing homes do not provide ventilator care). Steve reiterated that the Council and Advisory Committee are not advocating for the State to replicate nursing home care for those who need ventilator care as in OH and PA.

**Members’ Concerns:** Ann shared her concerns about the need for alternatives for care for aging parents and modern families who do not have a built-in support system.

Janice distributed information about a free seminar being sponsored by the UCED on February 27<sup>th</sup> at the Holiday Inn in South Charleston related to the rehabilitation of adults with traumatic brain injuries. She encouraged everyone to register to attend.

Clarice spoke about the recent closure of the Potomac Center due to the abuse/neglect of children served and WVA’s experience with the facility over the years. She stated “This is absolutely a dangerous facility for people with developmental disabilities,” and feels it is not qualified to provide the behavioral intervention services children are sent there to receive. She reported that the State sends people there who are waiting to go to out-of-state facilities and that often people are accepted there who do not meet the qualifications for an ICF level of care.

Steve reported he was asked to provide consultation at a retreat there several years ago for their Board of Directors, where he suggested they begin down-sizing in preparation for closing the facility. He also suggested they could not serve children and adults together in the facility. It now only serves children.

Clarice suggested the State should either make sure the Potomac Center is the treatment facility it is paid to be, or develop a way to support children with high behavior support needs in family settings.

**State Plan, PPR, and Data Issues related to planning/reporting:** In Jim's absence, Steve reported to Members about the Council's reporting requirements and the challenges faced due to the lack of data.

DD Councils have the highest obligation of the DD Network partners (Protection and Advocacy agencies and University Centers for Excellence in Developmental Disabilities) to report accurate and relevant information regarding the "State of the State." The Comprehensive Review and Analysis provides the rationale and justification for the Five Year Plan priorities and goals. The Federal program refers Councils to four sources to be used in reporting, but much of the WV data is missing in these sources.

Councils are specifically required to report about relevant services and supports provided by federally assisted State programs, particularly regarding eligibility, barriers, and degrees of support provided.

The Administration on Intellectual and Developmental Disabilities (AIDD) sets forth additional requirements for measuring the performance and impact of Council activities, and in the future – measurable changes within communities that have resulted from Council activities, partnerships, advocacy, etc.

Issues critical to people with developmental disabilities are relevant to all the Council's stakeholder agencies, and the Council's State Plan calls for the formation of an advisory group to develop methods for researching, storing, and sharing essential State DD information. Jim will be contacting Members in the near future to begin work on this objective.

Steve reported that the AIDD is piloting a project with 5-7 states to develop methods and models for data collection and outcome measurements. Clarice reported that the Protection and Advocacy agencies also have a pilot program with

6-7 states to develop standards for reporting. Janice reported that University Centers are using a new data system this year, and are looking at outcomes rather than numbers. Councils are also now required to look at outcomes.

Clarice reported that the reauthorization of the Rehabilitation Act currently includes language that would move Protection and Advocacy Programs and Vocational Rehabilitation Programs under the Department of Labor while Centers for Independent Living would be moved to AIDD.

**Status of grants/update on staff activities:** Steve reported that the Arc of the Mid-Ohio Valley was originally scheduled to give a presentation on their new grant to Members today. They will report at a future meeting.

He informed Members that following the October presentation by Job Squad, Inc. the project staff person and two others individuals associated with the project resigned. The project is continuing and is being managed by other Job Squad staff. Steve again requested the record to indicate the Council does not support the suggestions to hide assets as was made during that presentation.

He reported that the Director of the Fair Shake Network has resigned but will continue helping out while the organization looks for a new director.

The DHHR would not support the continuation of the project with the West Virginians for Affordable Health Care to develop the video which was being filmed during the October Council meeting. The video was unable to be completed during the previous grant cycle due to the lateness of decisions made by the State and other entities on how to meet the mandates of the Affordable Care Act (ACA). Council staff is working with DHHR Purchasing Division to develop a Request for Quotations (RFQ) in order to finish the video.

Ann Hubbs inquired about whether the Council still intends to solicit a dental study and will provide contacts of interested people. Steve affirmed that it is in our Plan and we continue to be interested in it.

Steve expressed interest in having a study completed on the I/DD Waiver similar to the recent study by the Business School at WVU on the economic impact of the Aged and Disabled Waiver.

Linda reported the highlights of her activities over the past quarter, including attendance at the TASH Conference in Chicago. She attended several sessions over the three day period, including a brown bag lunch with the Assistant Secretary of the Office of Special Education and Rehabilitation Services (OSERS), Sue Swenson. Secretary Swenson reported OSERS is currently working on the areas of seclusion/restraints, alternatives to guardianship, and transition. They are particularly interested in gather data on any families being locked out of IEP meetings unless they are guardians. She reported that this seems to be happening a lot to poor families.

Steve attended a Council Executive Directors' Retreat where he spoke with Commissioner Sharon Lewis about guardianship. It is also an interest of hers, and she reported that she was in discussions with the Department of Education to try to address the role education has played in encouraging families to apply for guardianship.

Christy reported that in addition to covering the legislative session and PIP, she is on the NACDD Public Policy Committee. She and other staff have been participating in conference calls related to employment, seclusion/restraints, and planned communities.

Council staff and several Members have also participated in webinars held by the Centers for Medicare and Medicaid Services (CMS) on the final rule recently released on Home and Community Based Services (HCBS).

**Changes affecting I/DD Waiver:** Pat Nisbet gave Members information on three recent issues affecting participants in the I/DD Waiver Program. Those include an IRS ruling, the Department of Labor ruling on companionship, and the recently released HCBS rule.

IRS ruling: Pat reported that following a conference call with the IRS several years ago, in which the State asked for a ruling on biological parents claiming a difficulty of care tax exemption, the IRS denied the exemption. However, this caused them to begin reviewing the situation and they have now reversed their decision. The difficulty of care exemption, which applies to foster care providers, will once again apply to biological parents who provide waiver services to their family member. Family members will continue to have other monies withheld from their reimbursement (such as federal medicare tax and social security tax).

This exemption does not apply to respite care services. It also does not affect the issue of whether or not family members are contractors or employees of an agency, which is a Department of Labor issue.

Pat reports she doesn't know if families will be eligible, but they should consult a qualified tax preparer if they want to file an amended return and request a refund for taxes paid in previous years.

Companionship Exemption: Pat referred to Fact Sheet 79F in Members' packets related to the requirement that overtime be paid for anything worked over 40 hours. She advised Members that anyone using the I/DD Waiver Personal Options (self-directed) will not be allowed to work more than 40 hours/week or be paid overtime. She advised that the changes will begin when Members have their six-month or Annual meeting between July and December, 2014. She stressed that hours of needed services will not be cut, but that any one staff person in the Personal Options program cannot work more than 40 hours, and suggested those who will be affected should begin looking for additional staff early.

Agencies will decide themselves whether or not to allow family members who are employees in the Traditional model to be paid overtime.

HCBS Rule: Pat provided a handout with information and spoke about the CMS final rule on HCBS. She pointed out to Members that another public webinar will be held on January 30<sup>th</sup> for anyone who is interested.

West Virginia's I/DD, A/D, and Traumatic Brain Injury (TBI) Waivers are all 1915(c) waivers. The state does not have 1915 (i) or 1915 (k) waivers. She reported that WV will not be combining the three waivers.

WV will have to develop a transition plan for any group homes, day programs, and sheltered workshops that do not meet the new requirements. States are given one year to develop a transition plan and five years to accomplish the transition once it is approved by the Secretary of Health and Human Services (HHS).

Some changes include:

Requirements for home and community-based settings are defined and described. Person Centered Planning and most integrated setting (as in Olmstead) is now mandated, and federal guidance will be provided.



Mandates that the person centered planning process be directed by the individual and may include a representative freely chosen by the individual.

Also excludes certain settings which are not considered home and community based.

Applies to all setting where home and community based services are provided – not just residential.

Requires the transition plan be put out for public comment two times.

The new rule is effective March 17, 2014.

There was discussion among the Members about various aspects of the changes. Ann expressed concern about the need for settings for those who are medically fragile. Clarice asked if the State would continue to require people to live with people they don't like. LuAnn expressed concern that this may deny people choice. Steve reminded members that as public stewards, the State has a responsibility not to promote bad public policy and to take certain settings off the table, as was done with the closure of Spencer State Hospital, the Greenbrier Center, and Colin Anderson Center. Amber stated this is a huge civil rights movement for people with developmental disabilities, and suggested BMS collaborate with the DD Council and folks who have been trained in Social Role Valorization/PASSING to survey settings and evaluate whether they are truly meet the criteria of HCBS.

Pat then announced that no one has been hired yet to replace her as the I/DD Waiver program manager, but Teresa McDonough was hired as the new program manager for the TBI Waiver.

**Feedback forms:** Kelly reminded Members to complete and leave the feedback forms.

**Adjournment:** Tara moved and Pat seconded the motion to adjourn.